

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

Dear Colleagues and Friends,

The year 2015 is coming to a close. A good year for EACME! We could gain a good number of new member institutes and we had the privilege to conduct our yearly conference in wonderful Cagliari, Italy. We want to say a heartfelt word of thanks to all those of our members whose great commitment and hard work contributes to the success of our association.

Along with this bright spots, the year also had its darker sides. The bomb attacks in Paris, and the multiple number of recent bomb threats certainly kept us question the status quo of our daily societal life and made us think beyond our daily tasks. I find myself asking the question: Should we try to have a say in this matters, as a society for “ethics”, or should we leave that to the politicians? An answer to this question is not easy. Sure is, this clash of cultures can be rooted in different values about the good life. And ethics is an expert discipline in reflecting about values and the good life. So maybe we – at least – have to put our expertise at proposal to those who want to discuss the often implicitly embedded values of our societies. Still, hasty answers might lead to superficialities, and maybe it is far more important task of ethicists to point out to those simplifications.

Let’s move to this newsletter at hand. You find text summaries of this year’s EACME price winner and poster winner of the Cagliari conference, Franziska Krause and Katja Kuehlmeier / Nina-Kathinka Schwenk. In addition, Yesim Ulman is reporting on the International Conference on “Emerging Technologies and Human Rights”. Jean Martin, Benoît Eyraud/Jean-Philippe Cobbaut and Nunziata Comoretto are rounding off this issue with topics stretching from assisting the elderly to equal rights of disabled to exercise civil and political capacity. Last but not least,

a memorial written by Paul Schotsmans reminds us of the death (and life!) of Maurice de Wachter.

The editorial team wishes you a pleasant reading, a festive season, relaxing holidays and a happy New Year 2016!

Rouven Porz – Editor EACME Newsletter

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EACME PRIZE WINNER 2015 FRANZISKA KRAUSE

The Ethics of Care and Emmanuel Levinas

During the 2015 EACME conference "Clinical Ethics: Past, Present and Future" in Cagliari I had the great opportunity to give a talk about some main insights from my PhD thesis. My presentation "Ethics of Care and the Concept of Relational Autonomy" was awarded with the EACME prize for young researchers and I would like to take the chance offered by the editors of the EACME newsletter to elucidate shortly what my PhD thesis "Sorge in Beziehungen" (care in relationships) is about.

Nowadays, the ethics of care is not as unknown as it was in the 1980ies when Carol Gilligan published her work "In a Different Voice" (Gilligan 1982) and a discussion arose whether a masculine justice-oriented and a feminine care-oriented perspective in ethical deliberation existed or not. The topics within the field of the ethics of care have expanded over the years and include social and political perspectives as well as issues related to medical and clinical ethics. A central and common characteristic of all approaches to the ethics of care is the intent to provide an explanation of what it means to care and in what respect care is part of flourishing relationships. However, there remains an ongoing discussion among care ethicists about the philosophical foundations and to what extent this ethical theory is applicable to moral deliberation and practice.

In my thesis I pursue the idea that Emmanuel Levinas' philosophy can offer an analysis of why people should care at all and what such an understanding of care can contribute to the ethical discourse. After a brief description of the developments and central ideas of the ethics of care, I develop four characteristics of care, taking into account the philosophical traditions they relate to.

These characteristics are:

- 1) Care is an important part of the *conditio humana*.
- 2) Care includes the disposition of empathic concern.

- 3) To care about another person is a moral duty.
- 4) Care is embodied.

Having in mind these characteristics and other definitions of care, the other person obviously plays a crucial role in the process of caring. However, almost all discussions about caring start from the perspective of the care-giver and not the care-receiver (Tronto 2013, p. 150). This is the point where my PhD thesis offers important insights into the ethics of care by taking up the philosophy of Emmanuel Levinas in order to explore the importance of the other person in caring attitudes and practices.

For Levinas, ethics is the first and most important discipline of philosophy. He describes ethics as an intersubjective relation beyond the need of any consciousness, knowledge or reflective ability. Hence his understanding of ethics differs from traditional ethical theories. It is neither based on a Kantian idea of self-legislation, the calculation of happiness like in utilitarianism nor the cultivation of virtues (Bergo 2011). It is best understood as a proto-ethic. This means that its focus is based on the question what it takes to understand ethics and why persons should be moral at all. In an ongoing process of perceiving and interacting with the world, the self finds what it means to be ethical. However, the world and others are not 'readiness-to-hand' (Zuhandenheit) as Heidegger would call it, but the self is deeply intertwined with others. Being-with-one-another is an ontological dimension of a person and not just a social fact without any impact on the self. The interaction that takes place between the self and the so-called Other is the starting point for ethics. It is an ethical relation insofar as the relation is based on responding to the Other by taking on a non-delineable and endless responsibility (Lévinas 2008, p. 317; Lévinas, et al. 2005, p. 177-178).

Levinas concept of the Other was often criticized for its vagueness concerning concrete ethical implications and its over-estimation of the influence of the Other on the self. Levinas' ethics seems to be inadequate for moral deliberations and conclusions, e.g. in the context of medical ethics, because it does not provide principles or rules for comparing situations. However, (the later) Levinas is quite aware of the fact that principles like universality and impartiality are important and that the Other is not representative of all kinds of relationships we live in. The passages of his oeuvre about "the Third" offer an idea of how to think about impersonal and non-dyadic relationships, which do not have the same characteristics as the relationship between the self and the Other. Levinas shows that being ethical means to accept the demand to treat people as if they were like the Other, though. It is an ongoing task in all kinds of relationships to be aware that people are unique and irreplaceable. This analysis of Levinas, as I show in my

PhD thesis, can have an impact on the way we think about ethical challenging situations, also in an international context where relationships exist that are not dyadic or personal.

Therefore, my last chapter takes a look at the international practice of surrogate motherhood. Surrogacy is illegal in most (European) countries, but in times of globalization couples with an unfulfilled wish for a child have the opportunity to travel to countries in the global south, e.g. India, and to become parents there with the help of a woman who carries their child to full term. A lot of relevant ethical questions arise in this context of reproductive medicine: Are surrogates object to financial and emotional exploitation? Do they fulfill the requirements for informed consent, i.e. do they have all the information they need to make a life-changing decision like that? Is surrogacy a form of commodification and is it therefore a sign for a loss of values in our society? Is it harmful for the child to have several mothers (genetic, biological, social) and to be born as a product of a contract between the surrogate mother and the commissioning parents? What Levinas' notion of the role of the Other can contribute to this discourse is not a totally new evaluation of the practice of surrogacy per se, but rather a shift in emphasis to the role of the parents-to-be in this "baby business" (Donchin 2010, p. 323). The responsibilities they have towards the surrogate are scarcely mentioned in the ethical reflections, but are obviously one main reason for the existence of the practice of surrogacy. In my work I show how this responsibility the parents-to-be have towards the surrogates is undermined by the fact that responsibility is not seen as an ethical demand of every single person who willingly or unwillingly engage in a relationship. It is rather considered as a mere legal responsibility that is restricted to the content of a contract.

As shown, Levinas illuminates that the Other plays a crucial part in the self-understanding of a person and in what it means to act ethically. Surrogacy as it is practiced all too often today, shows a lack of recognition of the Other and therefore a lack of responsibility and care in our society. A look at the ethics of care in the ethical discourse can foster a sensitivity for the complexity of challenges in the field of medical ethics. In addition to referring to principles or rules the ethics of care shows the importance of caring relationships for the individuals and for society as a whole.

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PREFERENCES FOR ADVANCE CARE PLANNING (ACP):

A qualitative study with former mental health service users

During the EACME ANNUAL CONFERENCE 2015 in Cagliari the presentation of our poster was awarded with the EACME POSTER Prize. We are grateful for the opportunity to present the readers of the EACME Newsletter with a summary of our presentation.

Background: According to the Society for Advance Care Planning and End-of-Life-Care (ACPEL) advance care planning (ACP) is defined as "a process of communication between individuals and their healthcare agents to understand, reflect on, discuss and plan for future healthcare decisions for a time when individuals are not able to make their own healthcare decisions". ACP is a complex intervention. It allows us to honor the right to self-determination in times where a patient is unable to decide for himself. In mental health it is used to establish and document treatment preferences for times when a user of mental health services has a mental health crisis and lacks decision-making capacity. Health care personnel are obliged to respect patient autonomy. But in mental health and especially in psychiatry it has been questioned whether doctors should always respect the wishes of their patients, even wishes that are written down in documents. This leads to the ethical question, whether health care personnel should respect expressions of autonomy of mental health service users in the same way as they should respect the expressions of autonomy of users of other health care services. Our study aims to inform this question, but not to answer it. We pose the research question: How do former mental health service users utilize documents for the ACP of future mental health crises? Our study aims to describe examples of current practice. The description of single cases allows us to explore, why these documents do not have the same acceptance in the field of mental health, as they have in other medical fields.

Methods: We used qualitative methods in order to be able to describe the current practice through the users' eyes. We gathered data through audiotaped semi-structured interviews and made anonymized copies of documents. We selected our participants through purposive sampling. Most participants were accessed through self-help groups of former mental health service users. The recruitment of participants was very difficult, because it was hard to identify potential participants, and overcome their lack of trust in medical research. It took approximately two years. Inclusion was based on the participants' statements of having a document to plan for future mental health crises. We excluded persons from the participation in our study who were in an acute mental health crisis. Participation was voluntarily and the data was anonymized as soon as possible. We used qualitative content analysis to analyse both sorts of data (documents and interview transcripts). The local ethics research board found the study to be unobjectionable. Here we describe the data of two participants to compare how exemplary users utilize ACP in mental health.

Results: We interviewed eight participants from different cities in southern Germany. From our eight interviews, we choose two cases that used the same category of documents which can be translated into English as a "treatment agreement for crisis" (German: Behandlungsvereinbarung). Usually, this document is the result of a negotiation between representatives of a psychiatric hospital and a (future) patient.

Our participants were both adult men with a prior diagnosis of psychosis, the first in connection with a bipolar disorder the second with a diagnosis of schizophrenia. Both experienced at least five stays in psychiatric hospitals over the last 10 years.

Both participants were the lead authors of their document and had several conversations with health care personnel about them. In their documents, both participants formulated wishes concerning crisis medication & coercion. The first participant refused a specific neuroleptic, mechanical restraint and agreed to specific drugs being administered. In the interview he said, he had a traumatic experience in the past, where he was restrained without watch and suffered an asthma attack that he wanted to preclude during future hospital stays. If restraint should be inevitable, the participant prefers medical sedation to mechanical restraint. The second participant did not report any traumatic event in the past. He agrees to a specific neuroleptic in a specific dose in cases where it can improve quality of life. If restraint is inevitable, the participant prefers isolation to mechanical restraint to medical sedation.

Although, the two participants were comparable with respect to certain characteristics and treatment preferences, they articulated very different preferences with regards to the decision-making process. The first

participant chose a surrogate decision-maker to enforce his decisions. When necessary, he wished for legal enforcement of his plan. He therefore made irrevocable decisions on future treatment that he wrote down in his document. The second participant chose a relative to be there for him and support him during future psychoses, but not to enforce his wishes for him. He wanted to use the document as a starting point for negotiations over the dosage of his medication. He did not make irrevocable decisions in advance, but wanted shared-decision-making between himself and the medical team during his next crisis, even in case of lacking capacity.

Conclusions: Documents for the ACP of future mental health crises that might have the same label are used in very different ways, with differing purposes. The two cases here seem not to pursue irrational aims, but the means with which they pursue those aims should be scrutinized further. It is hypothesized, that the confusion of aims of documents for ACP and not the expressed wishes of their users are the main reason for their low acceptance in mental health.

Acknowledgments: This is an early publication of partial results of a dissertation at the Medical Faculty of the Ludwig-Maximilians-Universität Munich. We thank the participants of our study, Lehre@LMU for funding and Corinna Klingler for her feedback.

We encourage you to share your impressions of our study with us.

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REPORT ON THE INTERNATIONAL CONFERENCE ON "EMERGING TECHNOLOGIES AND HUMAN RIGHTS"

**Council of Europe Bioethics Committee, DH-BIO,
Strasbourg, 4-5 May 2015**

Yesim Isil Ulman*

Emerging Technologies at a glance

Emerging Technologies have always been the dynamics of scientific advancement. Human Genome (HUGO) Project (2003) is one of the remarkable developments branding the 21st century at its dawn.

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Successive developments in life sciences such as regenerative medicine, genetics, organ transplantation, assisted reproduction, prenatal screening and testing, neuroscience, omics technologies (genomics, proteomics, etc) have opened new horizons for human welfare and health as well as debates on their ethical implications. Ethical, Legal and Social Implications (ELSI) Research Program which was established as an integral part of the Human Genome Project, therefore, aims to foster basic and applied research on the ethical, legal and social implications of genetic and genomic research for individuals, families and communities. Over the last few decades biotechnology and bioscience have brought remarkable discoveries in so many areas such as human embryonic stem cell biology, genetic modification of plants and animals, nanotechnology, neurosciences, and synthetic biology. On the other hand new areas of science often bring controversy along with their promise⁽¹⁾.

Can we, even, edit human genome?

In April 2015, there happened to be a new lane in the track of precision gene editing techniques to the human germline. A Chinese group stated that they had edited the human genome and published that they had successfully modified the genomes of human embryos. The National Institutes of Health (NIH) declared it would not fund such research. Then in September, the U.S./U.K.-based Hinxton Group, an international consortium of scientists, policy experts, and bioethicists, said it supported the use of genetic editing in human embryos for limited applications in research and medicine^{(2), (3)}. The ability to precisely edit the genome of a living cell holds enormous potential to accelerate life science research, improve biotechnology, and even treat human disease. The prospect of rapid and efficient genome editing raises many ethical and societal concerns, says Zhang, who is speaking at the International Summit on Gene Editing in Washington. "Many of the safety concerns are related to off-target effects," he says. "We hope the development of eSpCas9 will help address some of those concerns, but we certainly don't see this as a magic bullet. The field is advancing at a rapid pace, and there is still a lot to learn before we can consider applying this technology for clinical use."^{(4), (5)}

The Council of Europe's Committee on bioethics DH-BIO stated the Oviedo Convention as the only international legally binding treaty addressing human rights in the biomedical field. Article 13 of the convention limits the purposes of any intervention on the human genome, including in the field of research, to prevention, diagnosis or therapy. In addition, it prohibits any gene modification of embryos that would be passed on to future generations⁽⁶⁾.

Council of Europe and Committee on Bioethics (DH-BIO)

Human rights and dignity is the key to elucidate the ethical approach to new emerging technologies. The Council of Europe, addressed a variety of developments in the field of biomedicine in the past decades. While recognising these developments as a potential benefit for human health and welfare, the Council also realises the possibility of abuse as a reason for concern from the perspective of human rights and human dignity. On the basis of the common framework provided by the European Convention on Human Rights and Biomedicine, or Oviedo Convention (1997), the Committee on Bioethics of the Council of Europe (DH-BIO) has considered various ethical and legal challenges raised by the applications of biology and medicine.

In recent years innovations in the biomedical field are more and more emerging from the convergence of developments in different domains, including nanotechnology, cognitive science and information technology. As a result of this convergence, we can observe an increasing interaction between the life sciences and the engineering sciences. This interaction and convergence between different scientific and technological fields also raises new questions about the implications of these developments for human rights and human dignity⁽⁷⁾.

CoE's International Conference on "Emerging Technologies and Human Rights"

The International Conference on Emerging Technologies and Human Rights was organised by DH-BIO on 4-5 May 2015 in Palais de l'Europe, Strasbourg, France under the auspices of the Belgian Chairmanship of the Committee of Ministers.

The Conference promoted interdisciplinary debate with lawyers and experts in Human Rights, scientists, sociologists, philosophers as well as other experts in fields concerned. There were approximately 200 participants who were invited to take part in the debate⁽⁸⁾.

After the inaugural speeches, the scientific sessions started, Dr. Anne Forus, Chair of the Preparatory Group for the Conference, introduced the objectives of the Conference.

By his speech called "Driving force for developments", Prof. Andy Stirling from University of Sussex Science Policy Research Unit, reviewed some key features of the dynamics driving the emergence of new technologies. He highlighted how the challenges presented for social justice. He argued that there are also profound questions over the directions taken by emerging technologies in particular sectors. This raises challenges around the 'opening up' of research and innovation – and recognising the crucial roles for social movements and civil society. The challenges for social justice presented by emerging technologies are not

just about distributions of risks and benefits around particular privileged trajectories. They are about democratising the directions of progress itself. He argues that there are three overarching principles: participation, responsibility and precaution. First, there is **public participation** in innovation. Secondly, major policy imperative is for all actors involved in research and innovation processes – especially the most powerful – to assume more direct and **explicit responsibility** for the consequences and uncertainties of their activities. Thirdly, greater and more deliberate efforts are needed to moderate the powerful forces of closure in science and technology. That is the particular value of **precaution** in regulation. Inter-related practices of responsibility among researchers and innovators, precaution in regulatory processes and participation in policy making and innovation itself, can help innovation escape from these restrictive fear-driven technical imperatives. They illuminate instead how innovation is fundamentally about the politics of contending hopes. Most importantly, it is in these ways that narrow technocratic ideas of a knowledge economy can give way to the nurturing of a more inclusive, rational and vibrant innovation democracy⁽⁹⁾.

Background Studies

Two background studies were prepared for the Conference, covering on the one hand the scientific aspects of new technological developments, and on the other ethical issues raised by emerging sciences and technologies.

Firstly, “From Bio to NBIC convergence – From Medical Practice to Daily Life”, Dr Rinie van Est and Dr Dirk Stemerding (Netherlands, Rathenau Instituut) highlight three technological trends which might be very relevant for the Committee on Bioethics. First of all, new types of developments are observed within the medical domain: from neuro-modulation techniques to molecular medicine. The study further shows that NBIC convergence enables the application of biomedical technologies outside the professional medical domain. Finally, it is seen that, as a result of this development, there is an increasing use of biomedical tools and bio-data for non-medical purposes, like gaming, entertainment, marketing, coaching, and human or social enhancement. They have five recommendations:

(1) The developments within emerging sciences and technologies pose serious ethical issues and concerns. The Council of Europe has an important role also in being a forum for continuous reflection and discussion needed to root the answers to the new ethical issues in shared European values and shared criteria for action. The scope of the bioethical work of the CoE should be permanently expanded to cover the developments in nano-, neuro-, info- and cogno- science and technology.

(2) In line with the European heritage of democracy, a significant task for bioethical work is to play a proactive part in the democratization of the production of sociotechnical imaginaries and thereby our common scientific and technological future, for instance by developing and encouraging participatory foresight exercises, upstream engagement and other practices of what has been called “responsible research and innovation” (RRI).

(3) Several technological fields call for continuous monitoring with respect to the ethical issues they pose. This includes human enhancement, persuasive and personality-altering technologies and other technologies that interfere with the preconditions for enjoying fundamental rights and freedoms. CoE is encouraged to take a proactive role in the development and harmonization of such ethical monitoring schemes and practices.

(4) In our report, we have observed threats to several fundamental rights and freedoms laid down by the Oviedo Convention as well as the Convention for the Protection of Human Rights and Fundamental Freedoms. A number of possible ways forward can be imagined, including new Recommendations on specific technological fields and even the expansion of the scope of the Oviedo Convention to the formulation of a new convention for ethics of science and technology that falls outside the medical realm. We have indicated the main fundamental rights and freedoms that we believe to be at stake.

(5) Another way forward is to discuss how measures can be taken when the normative basis and the legal instruments are present, but new practices in the world of science and technology are seen to systematically violate them. For instance, the report has raised the question if not the new phenomenon of mass data collection and surveillance as a business model indeed is a violation of fundamental rights and freedoms of citizens⁽¹⁰⁾.

At the second background study, “Report on ethical issues raised by emerging sciences and technologies”, Prof. Roger Strand and Prof. Matthias Kaiser (Bergen University, Norway) discussed three sets of scientific and technological developments as paradigmatic cases, labelled as neuro, nano and ICT, respectively. In the full report, they also briefly discuss three cross-cutting aspects: (1) the blurring of the line between the medical and the non-medical domain, (2) the ethical issue of global divides and equitable access and (3) the particular ethical challenges of military use of technologies. They recommend:

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Closing of the Conference:

At the second section of the Conference, Prof. Hub Zwart (Netherlands), Prof. Jean-Noël Missa (Belgium), Prof. Dominique Thouvenin (France), Dr Péter Kimpán (Hungary), Prof. Dr. Peter Dabrock (Germany/EGE), Prof. Yann Joly (Canada), Prof. Jan Helge Solbakk (Norway), Prof. Stefano Semplici (Italy/UNESCO), Dr Yolanda Gómez-Sánchez (Spain), Prof. Sheila Jasanoff (USA), Prof. Herman Nys (Belgium/EGE), Prof. Sheila Jasanoff (USA) and Prof. Herman Nys (Belgium/EGE) analyzed the issue regarding technology, intervention and control of individuals, data collecting and processing, equity of access, and governance. At the closing session, it has been decided to place the Conference reports and papers

on the web site of the Council of Europe DH-BIO in order to share the scientific data with the public and with concerned stakeholders⁽¹²⁾. This highly informative Conference has put forth that the illuminating key principles of bioethics are the underlying force of the universal human rights law that can guide humanity to overcome any abuse or violation on part of human dignity. Hence the main objective of biomedical sciences is to serve human health and welfare consolidated with the backbone of bioethics principles and participatory democracy.

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Please see the Bioethics Unit website: <https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=0900001680307575> (Accessed on December 6, 2015)
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<http://www.coe.int/en/web/bioethics/emerging-technologies>

REEMPLACER LA "PETITE ÉTHIQUE" ACTUELLE PAR UNE "GRANDE ÉTHIQUE" PLUS PORTEUSE DE SENS?

A propos de : Mark Hunyadi. **La tyrannie des modes de vie – Sur le paradoxe moral de notre temps.** F-33310 Lormont, Ed. Le Bord de l'Eau, 2015.

Mark Hunyadi, né en 1960, est un philosophe suisse. Après les Universités de Genève et Laval au Québec, il est professeur depuis 2007 à l'Université catholique de Louvain. Son dernier ouvrage lance un pavé dans la mare, appelant à substituer une « Grande éthique » porteuse de sens à ce qu'il appelle la « Petite éthique » (celle à laquelle s'attachent l'essentiel des travaux en bioéthique) qui à son sens sert à pasteuriser un système insoutenable. « Nous vivons un paradoxe si manifeste que nous ne le voyons plus. Une véritable inflation éthique, par la multiplication des comités, chartes, conseils, tous censés protéger les droits individuels, [fait que] des modes de vie de plus en plus contraignants, qui échappent à tout contrôle, étendent leur emprise. Tout ce dispositif sert à blanchir un système et les modes de vie qui en découlent. » Aussi : « C'est comme si nous luttions avec acharnement pour la liberté de choisir la couleur des briques de notre propre prison. »

L'éthique est vassale du système, dit-il. Nos débats éthiques servent-ils surtout de blanc-seing aux avancées tous azimuts des sciences et techniques ? Il y a là une question que se posent beaucoup de ceux qui se préoccupent de bioéthique. A quoi devrait ressembler, selon l'auteur, la « Grande éthique » nécessaire : il faut « renoncer à la neutralisation éthique du monde pour prendre ce monde même, sous toutes ses facettes, comme objet de son souci [...] Ce n'est pas la lettre des articles des droits de l'homme que nous défendons, comme le ferait un juriste procédurier, c'est leur sens, c'est-à-dire cette notion d'égalité dignité » (de et pour tous).

L'empereur est nu, s'agissant d'éthique globale, c'est ce que dit Hunyadi. Comment avancer mieux ? Formaliser et mettre en œuvre des droits « communautaires » (mais le mot n'est guère aimé dans certaines acceptions), « sociétaux » ? Mais on sait les difficultés qu'il y a à définir l'intérêt général,

même si d'une façon ou de l'autre c'est indispensable. Qui donne attention aux intérêts des générations futures – eux aussi difficiles à préciser, relèvent nos critiques ! Il reste vraisemblable que l'accent quasi exclusif mis sur des droits individuels toujours plus nombreux, et dont chacun exige la concrétisation, devrait être revisitée dans un sens moins égocentré, plus solidaire – étant entendu qu'on ne saurait jeter aux orties les acquis des droits humains. Promouvoir un changement de conscience et de pratiques de tous, en particulier des nantis, comment ?

Hunyadi demande - comme d'autres l'ont fait - la création d'une nouvelle Chambre, en complément au système politique bicaméral usuel. Un Parlement (virtuel) des modes de vie, « institution qui, instaurant le commun [à savoir une préoccupation centrale pour les biens et l'intérêt communs] ébranlerait le pilier de nos démocraties libérales, celui du partage strict entre une sphère publique devant obéir au principe de neutralité et la sphère privée où s'exerce le libre choix de chacun. » On peut penser que sa mise en œuvre rencontrera(it) des obstacles formidables : par la mise au défi du système démocratique où chacun vote pour l'essentiel selon son intérêt propre à court terme ; par le spectre d'une « République - despotique ? - des sages ». Même si la manière de concrétiser les propositions de l'auteur reste mal définie, on peut penser que (sous peine de fin d'histoire ?) il faudra trouver les voies et moyens d'une 'Grande éthique', planétaire, allant au-delà des seuls droits des individus.

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INTERNATIONAL CONFERENCE PARIS

Back to an International conference held in Paris on October 28-29-30 2015 on the United Convention on the Rights of Persons with Disabilities

Focus on Article 12 of the Convention: A Legal turning point in care and support relationships

Democratic societies are based on the principle of all citizens having **equal rights to exercise civil and political capacity** and to decide and to act independently for themselves.

In a number of cases when people are in vulnerable situations, this ideal of equal autonomy is put to the test, which may lead family members and professionals to intervene on behalf of another person,

sometimes acting in their stead. Traditional legal systems provide that this type of intervention must be in the person's best interests, which constitutes a **paradigm in regulating care and support**. With the UN Convention on the Rights of Persons with Disabilities (CRPD), this paradigm has changed.

Article 12, dealing with **legal capacity**, offers a new outlook and new legal rules applicable to persons in vulnerable situations. This Article has established that **a person's "own choices and preferences"** should be the legal basis for an entire series of decisions or actions taken in many fields (health care, employment, personal and family life, personal property, transportation, food, standard of living, participation in social life, etc.), rather than a person's "best interests" or "needs". Article 12 recommends that supported decision-making systems be mainstreamed so as to prevent decisions about people's lives from being made by others and to prevent the use of compulsion or force.

In order to contribute to the debate in the French context, Collectif Contrast, a French inter-disciplinary research organization specialized in sociology, law and philosophy, has organized an International conference that has been held in Paris on October 28, 29 and 30, 2015.

This Conference has brought together a wide variety of stakeholders interested in the implementation of the Convention: users of social or medical-social services, managers of care and social support facilities, service providers, psychiatrists, geriatric and general practitioners, nurses, health and social workers, court-appointed legal guardians, family member guardians, judges, lawyers, researchers and concerned citizens, among others.

This event has succeeded in drawing on the experience of international researchers, sharing the expectations of the various institutions for which the implementation of the Convention is relevant and of those persons actually in vulnerable situations, and giving a complex account of the issues and difficulties encountered by professionals in the field and at the level of public policy.

Three main focal areas have been discussed. The first consists in identifying the dilemmas and difficulties encountered by stakeholders in health care and support relationships. The second will analyze the tools and instruments used to assess situations involving persons in a vulnerable position, and particularly those used to qualify the legal capacity of persons with disabilities. The third point will focus on the stakes and challenges involved in action taken by the public authorities.

This conference is the first stage of a collaborative approach that will be proposed among relevant stakeholders.

Providing a platform for information and exchange among academic researchers (sociologists, Legal specialists, Philosophers), persons with disabilities and their representatives, professionals working in the field and members of civil society.

Article 12 itself and the General Comment on Article 12 issued by the UN Committee on the Rights of Persons with Disabilities have been highly debated among academics and international activists.

The objective is to provide a platform for information and exchange on the impact of Article 12 of the Convention, from the standpoint of its symbolic importance and above all, the difficulties and stakes involved in full implementation.

This collaborative initiative is supported both by official bodies in charge of monitoring the implementation of the Convention and by a Steering Committee composed of representatives from public-sector institutions and scientific advisors who will provide guidance with governance and dissemination of the results of this project.

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"ASSISTING THE ELDERLY AND PALLIATIVE CARE WORKSHOP

**XXI General Assembly of the Pontifical Academy for Life
Vatican City, 5 – 7 March 2015**

The workshop sought to promote research on the role of palliative care in assisting the elderly and ethical, social and cultural implications relative to it.

Session I – Clinical Care For the Elderly at the End of Life

The workshop began with a presentation from H.E. Msgr. Ignacio Carrasco de Paula, President of the *Pontifical Academy for Life* entitled, "The Challenges of Assisting the Elderly at the End of Life". In modern culture, we do not always find adequate means to face the specificity of the problems that the elderly encounter. The "social" value of the elderly has

their “ontological” value as an ineludible premise: existing as a person, as someone who deserves to be loved unconditionally. Love and care for the elderly have, as for every human being, their proper place within the family. Along with this place within the family, there should also be, however, concrete expression of this care within the entire community, according to the principle of subsidiarity. The elderly also manifest the truth of the human person as *ens indigens*, an anthropological paradigm welcomed by palliative care as its essential core. Palliative care is not a type of philanthropic “charity” or concession, but is an expression of that which is truly human.

Dr. Armando Garcia Querol (Buenos Aires, Argentina) presented on the theme of “Elderly at the End of Life Due to Chronic Degenerative Illnesses”. The patient can live through the deterioration associated with the final stages of chronic illnesses in a dignified manner when science and medicine are utilized in such a way that takes into account the unique nature proper to the individual patient. Palliative care can bring important benefits to the patient’s overall physical and social stabilization, alleviating thus at the same time the stress upon the family members committed to the long term care of the patient.

Professor Joan Panke (Washington DC, USA) spoke on the theme of “Nursing Care for the Terminally Ill Elderly”. The work of the nurse combines the science of nursing and the art of giving care. For this reason, the personal relationship with the patient lies at the heart of the profession. Notwithstanding the diversity of expressions that the profession takes throughout the world, human nature and respect for human dignity are foundational principles that hold universal value in the nursing profession.

Prof. Paolo Preziosi (Rome, Italy) spoke upon the theme of “Use and Abuse of Analgesics in Palliative Care”. Greater caution is required when these medications are utilized in the treatment of the elderly. In the United States, for example, between 1999 and 2010, deaths linked to the abuse of prescription pain medication quadrupled.

In closing the first session, Prof. Daniel Sulmasy (Chicago, USA) presented upon “The Process of Clinical Decision-Making for the Elderly at the End of Life”. Medical action is an ethical endeavor where dignity and finite nature of the human person meet. Therefore, clinical decisions thus must always take into account the specificities proper to each individual case. This is possible without falling into relativism. It is the fruit of prudence. The duty of those who assisting in this care is not only that of helping to make the decisions regarding which treatments to undertake or

not, but to seek an environment in which the person may grow in a holistic sense.

Session II: Ethical-Anthropological Perspectives

The second session began with a presentation from Prof. Pierre Boitte (Lille, France), on the theme of “The Central Role of ‘Relationships’: The Elderly, Healthcare Worker, Family and Society”. The expression of relationality in the medical field has definitely undergone changes due to the increase of technology used in medical care. The physical and spiritual suffering of illness can often lead to the depersonalization of the patient as well as the family. In response to this, the reality of being in relationship can reduce this isolation and allow the patient to be welcomed in the fullness of his or her personal reality. The value of relationship can be grasped only if medicine returns to providing care and not merely technical interventions. This dimension of care must be present not only in individual relationships, but also at the institutional and societal level.

Prof. Adriana Turruziani (Rome, Italy) made a presentation entitled “Beyond Verbal Communication in the Care of the Elderly Patient”. Nonverbal communication has the capacity to reveal deeply held sentiments of the person. In care for the elderly, it allows for a real and dynamic relationship. The patient can communicate his or her needs and wishes through facial expressions, body movements, posture and eye movements. It is particularly important for the team that is assisting to be able to recognize nonverbal signs associated with the presence of pain.

Prof. David Roy (Montreal, Canada) presented upon “Ethics and Palliative Care for the Elderly”. The human being, by his or her very nature, resists death and its dominion, even in its most fragile and vulnerable state, in such a way that no medical act can negate. When seeking to approach the situation from an ethical perspective, one must keep in mind the complexities involved. Many times, abstract principles do not suffice for an adequate consideration of these situations, nor are the modes of reasoning built upon these principles. Prof. Roy considered at least two assumptions present in contemporary palliative medicine: 1) the pretense of “taming” human suffering by pharmacologically controlling it until induced death; 2) the pretense of controlling human death, due to its interdisciplinary nature. Situations may be considered here as well in which the elderly are victims of dehumanization and discrimination - even unto imposing a “duty to die” upon them - excluding them from those entitled to remain within human society.

Prof. Carlos Centeno Cortés (Pamplona, Spain) then spoke upon “Advanced Care Planning”. This

notion has to do with the relational process through which a treatment plan is designed, taking into account the future evolution of the illness. The planning process, which can also be documented, emphasizes the relational process preceding the decision and treatments to undergo. The principle roadblock to prior planning of care is perhaps the prevalent attitude of giving of minimal information to the patient. This decisional process also has a heightened ethical value for those in clinical medical professionals involved, in the sense that it allows the patient to have the experience of being truly accompanied through the final stages of life.

Prof. Chris Gastmans (Louvain, Belgium) then spoke upon "Worrying Tendencies in the Care of Elderly Patients with Dementia". There are many cultural elements that do not allow for the licit practice of euthanasia within medicine and society at large: the recognition of the intrinsic and thus inviolable dignity of the human person; the recognition of the value of that autonomy formed in relationships, meaning thus that it cannot be considered abstractly as some sort of requirement pertaining solely to the individual; a quality of life that takes into account the personal perspective of the patient and that is not confused with the perspectives that other people have regarding the patient; and the ideal of "caring" as forming part of our anthropological structure and thus for this being an ethical duty.

Rev. Prof. Leocir Pessini (São Paulo, Brazil) concluded the session with his presentation upon "Ethical Guidelines for Good Accompaniment". The myth of eternal youth and the possibility of immortality expounded within contemporary scientific culture pose an ideological challenge that is particularly frustrating for the medical healthcare field dealing with the elderly. From this awareness also proceeds recognition of solidarity as a personal and professional value, as well as a true social virtue.

Session III – Socio-Cultural Perspective

The session opened with a presentation by Rev. Armando Augiero (Rome, Italy) on the theme of "Elderly at the End of Life: Spiritual Aspects". The elderly today receive much counsel regarding care for the body though not for the soul. There are important existential questions to consider: what does it mean to be elderly, how to face fragility and abandonment, as well as what kind of outlook there is for the elderly. Antidepressant medication is not the solution, but the reconstruction of one's own mode of looking at one's self and interpreting the world. These profound needs are religious (prayer, turning to God...), existential (speaking of the meaning of life and suffering, of life after death), and above all for interior peace and the

ability to work for the good by giving themselves in some way to others.

Prof. John Keow (Washington DC, USA) then presented upon "Legal Issues at the End of Life". There can be legally relevant problems posed by the refusal of care. Discrimination based upon the quality of life is particularly worrisome with regard to the elderly and more so even for elderly persons diagnosed with dementia. The reality that this discrimination leads to a slippery slope for the elderly has been amply demonstrated.

The Rev. Dr. Tomi Thomas (Secunderabad, India) then presented upon the theme of "Pastoral Care and the Role of the Family". Concrete needs and modes of assistance can often be particular to the specific socio-cultural context in question. In India less than 2% of the population receives palliative care that adequately meets their needs. In this context, palliative care as well as pastoral care is best given through home based services having teams and networks of volunteers from within the local community.

Prof. Marco Trabucchi (Rome, Italy) then presented upon the question of "What is Social Solidarity? The growing economic difficulties associated with the social and demographic changes require a change in the approach that society takes toward caring for the elderly, above all with regard to public assistance. It is necessary to promote medical research for the prevention of chronic illnesses and the disability associated thereto, but also to develop highly technically competent health care workers who serve the elderly with real compassion. Finally, it is necessary to promote an attitude of solidarity at the community level that supports families caring for their elderly, above all for the most difficult cases as in the elderly persons with dementia.

Pope Francis, in his discourse to the participants of the General Assembly, spoke upon developing an attitude of authentic solidarity toward the elderly.

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RECENSION

Recension de

Martin DUMONT

L'annonce au malade

Paris: PUF (Presses universitaires de France), 2015, 102 pages.

Ce petit ouvrage bien écrit traite du moment majeur de la relation médecin-malade qu'est la communication, particulièrement, d'un diagnostic grave voire funeste (cancer, maladie dégénérative sévère). Son auteur est un agrégé de philosophie qui y développe une communication faite devant des spécialistes de la sclérose en plaques – ceci en démontrant bien connaître les fondamentaux de l'éthique médicale. Analyse d'un spécialiste de la communication et du langage qui est susceptible d'intéresser vivement les médecins et d'autres professionnels, en les amenant à réfléchir à cette « scène » cruciale de l'histoire partagée du soignant et du soigné.

L'ambition est de mieux procéder à ces annonces, « non pas en simplifiant par magie mais en refusant d'en rester à l'idée que 'de toute façon, il n'y a pas de bonne façon de faire' ». Le chapitre I décrit les tensions et violences autour de ce moment. Le chapitre II traite des écueils y relatifs, discutant trois éventualités : annonce brutale (une maltraitance), escamotée, ratée. En rappelant Aristote disant que le véritable courage ne doit céder ni à la témérité, qui mène à des risques déraisonnables, ni à l'excès de prudence qui fait sombrer dans la lâcheté.

Du point de vue du patient : se souvenir qu'une dimension du traumatisme de l'annonce réside dans le sentiment d'injustice qui s'éveille chez le patient, « auquel il faut s'efforcer d'apporter une réponse, ne serait-ce qu'en reconnaissant qu'il y a bien dans la maladie une forme d'injustice. » D'où, parmi d'autres raisons, l'importance de l'attention, de l'empathie. Avec cette phrase de Simone Weil : « Les malheureux n'ont pas besoin d'autre chose en ce monde que d'être humains capables de faire attention à eux. Cette capacité est chose très rare, très difficile ; c'est presque un miracle. » Autre aspect : « Les patients savent que le fait d'annoncer est difficile pour les médecins. Ils sentent la capacité ou non du médecin à être touché par ce qu'il a à dire et par la personne à qui il le dit (...) Le médecin doit sans cesse être reconduit au caractère inconfortable de la situation, n'étant ni lui-même détruit par l'annonce, ni devenu insensible à celle qu'il doit faire. »

Un point spécifique, la difficulté de l'information (qui reste optionnelle) par le malade à ses proches. « En effet, les patients peuvent subir une stigmatisation du fait de leur maladie, ce qui les rend prudents, alors même que l'annonce à l'entourage permettrait de trouver du soutien, ou d'expliquer des symptômes socialement embarrassants. » On a là une

problématique de type « coming out » - qui ne se pose donc pas seulement dans des situations VIH/sida.

Au chapitre III, il faut recommander la section « Peut-on mentir ? ». Remarquable démonstration (la plus forte que je connaisse en français) du caractère injustifiable du mensonge dans la relation de soin - sous réserve de rares situations où il peut être admissible d'introduire un délai (limité) ou d'informer par étapes. Mais la faculté accordée au médecin, dans des déontologies anciennes, de choisir arbitrairement ce qu'il dit et quand, en occultant tout ou partie de la réalité, est inconciliable avec les droits et les intérêts du patient - et le respect qu'on lui doit. « Mentir consiste inéluctablement à amputer autrui d'une part de sa liberté ». Ceci sans compter le fait d'expérience que ceux à qui on ment s'en rendent compte, sans oser le dire, et sont alors laissés à leurs incertitudes et leur désarroi.

Après l'annonce : Il y a la parole et il y a aussi, qui se poursuit, l'action (le soin), ainsi que le silence - souvent nécessaire, bénéfique : « suite aux paroles difficiles de l'annonce, aux paroles consolatrices qui ont pu être prononcées, vient le temps plus silencieux et plus objectif du soin. » « S'efforcer que le patient retrouve, malgré l'annonce funeste, un rapport apaisé au temps qu'il vit (...) par des biens vécus au présent et non dans les promesses d'une amélioration future peut-être illusoire ».

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IN MEMORIAM: MAURICE DE WACHTER



In Memoriam: Maurice August Maria De Wachter
 * 10 December 1930 – † 3 October 2015
 President EACME: 1992 - 1998

Maurice De Wachter was and remains for me “Mister Bioethics Europe” and even more “Mister EACME”. Although he belonged to the founding fathers (and mother) of EACME, he made the choice not to be the first President: he left this honor to Nicole Léry of Lyon, yet illustrating by this choice his dream to make from EACME a dynamic and open Association.

He represented Maastricht in the Board and as such, he combined many geographical connotations: from Flemish-Belgian origin, working first at the Catholic University of Leuven (KU Leuven), the Radboud University of Nijmegen, later in Montréal and having excellent contacts with North-American bioethicists, coming to Maastricht for taking up the direction of the Institute for Bioethics. Maurice was also trained to be an excellent scholar in the context of the Jesuit Society, which he left for his beloved Nancy and – later on – their beloved daughters Rachel and Ellen.

Maurice was my companion during many trips and meetings: not only inside EACME (although they were the most important ones), but also many meetings of bioethicists all over the world.

What many do not know, is that Maurice played a great role in a (discrete and quasi unknown) advisory working group of bioethicists inside the International Federation of Catholic Universities. This organization (IFCU-FIUC in French) had a subsection for those universities with a university hospital. He was a very active member of this group and hosted even many meetings in Maastricht. Other members of the group were - besides the chairperson John Collins Harvey (Georgetown) - Francesc Abel (Barcelona), Edouard Boné (Brussels), Jack Mahoney (London) and Patrick Verspieren (Paris). I could attend as a young scholar these fantastic meetings and thus enjoy the richness of their deliberations (hoping to influence some – more open – Cardinals of the Catholic Church).

Even earlier, as a young theological scholar, I missed him in 1973 (when I started my theological studies, he just left the KU Leuven). Although his relationship with the KU Leuven was difficult, I could build up with him a very strong (first) professional and (later) friendly relationship. Our purpose was indeed the same: the growth of EACME. It was for me then really a wonderful occasion to give him in Leuven the floor for the celebration of the 20th anniversary of EACME.

I remember many wonderful things from him. He was an excellent board member of EACME, very devoted to the Association, and also an inspiring President. I worked with him as treasurer and secretary-general. We were both present at the important Congress in London, where the International Association of Bioethics (IAB) and EACME met each other (and this

in the symbolic year 2000). One of his dreams was indeed that EACME should really take its place inside the IAB.

Maurice was always extremely well prepared, punctual, multi-lingual, discrete but collegial...I cannot imagine EACME to have grown in the way we observe it now, without him. He was an excellent bioethicist: his contributions on the Convention on Human Rights and Biomedicine (Council of Europe) are crucial for the understanding of this important document. During the nighties, he clarified for the whole world the Dutch regulations and practices on euthanasia. Maurice loved accuracy: he corrected indeed many misunderstandings on these evolutions in Holland.

Some illustrations may make this in memoriam more colorful. During his time as President, we went for our Bureau meetings to Paris (Patrick Verspieren’s Centre Sèvres). At that time, it was a long journey for everyone, except of course for our host Patrick. We didn’t travel together (there was always some distance), but exactly at noon time the Bureau started, and punctually at 4 PM it was finished, so that everyone could get back home the same day. It was sober: one sandwich; it was perfectly prepared and therefore efficient (Maurice hated inefficiency); it was also highly delightful (with Emilio Mordini and Patrick Verspieren). At a certain time, he proposed we should stay at least once for the whole weekend and really enjoy Paris by night as also the Parisian gastronomy. We were surprised, but it was wonderful: this initiative made us stronger and helped us to strengthen our collaboration in favor of EACME.

Another incident I will never forget: we stayed with many EACME members in the same hotel for an annual meeting. We had to leave very early (5 AM) to go to the Airport. The hotel manager refused however to make our bills the night before: this would be done in the morning. Maurice previewed difficulties and waited on his own more than two hours after midnight. He finally could manage that the hotel manager showed up and made our bills, so that we could leave in the morning on time.

I will remember him and keep this memory in my heart as a real companion, a highly experienced “leader”, an excellent scholar and an open mind. May he rest in peace! I – and certainly also the whole community of EACME - present my sincere condolences to Nancy, Rachel and Ellen.

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